

Self-Direction and Employer Management

How to Partner with Agencies and Staff

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Purpose:

The purpose of this session is to empower consumers with disabilities and their caretakers with information that will help create a better quality of life, not only for the consumer with disabilities but also for their caretakers, families and others involved in their life.

There will be information and resources shared here that will allow a consumer to learn how to Self-Direct their services and manage their employee/caretakers along with information for caretakers on how to help their consumers by being a better advocate for them.

The term "Self-Directed" is sometimes also referred to as, "Participant-Directed," "Consumer-Directed," or "Veteran-Directed."

Medicaid Service Delivery Systems

Kansas has 3 service delivery models for the Home and Community Based Services that include

- Self-Directed Services
- Agency-Directed Services
- A combination of the two

Self-Direction Defined:

You can find a complete definition of Self-Direction on the following site:

www.Medicaid.gov

In summary, it states that Self-Directed Medicaid Services means that participants, or their representatives, have decision-making authority to manage their services. Self-direction promotes personal choice and control over the delivery of waiver and state plan services, including who provides the services and how services are provided. In other words, you will recruit, hire, train, supervise and fire the individuals that work for you. If you receive Medicaid funding, like SSI or SSDI, you will also make decisions about how that Medicaid money is spent. Think of the self-directed service model as the opposite of the traditionally managed services, such as a nursing agency that will train, hire, fire and schedule the caretakers to come to the house to assist. Self-Directing your home and community-based services will allow people of all types of disabilities maintain their independence and determine for themselves what mix of personal assistance supports and services work best for them. Some people will need assistance from his or her family or a representative in order to make decisions and that is ok too.

Definition Summarized:

Choice is the hallmark of this service delivery system, meaning individuals have the choice to:

- Direct their own services with assistance and support as needed from a representative.
- Make decisions about services and supports that are meaningful to the participant.
- Control personal outcomes through the delivery of this service model.

Brianna's History

During my pregnancy, Brianna was a Transverse Breech and at birth was born dead due to perinatal asphyxia due to a prolapsed cord at home. We had an emergency C-Section and she was resuscitated after 8 minutes with a faint heartbeat. Her apgars were 0, 0, and 3 after 10 minutes and EEG was a flatline.

She had no reflex for sucking and swallowing and didn't respond to sights or sounds.

She spent 7 weeks in NICU on and off vent, struggling to survive



Brianna's History, Cont'd

Because of Brianna's inability to swallow her own saliva, her first few years consisted of frequent aspiration pneumonia. Because we had good partnerships with our Home Health Agencies and Nurses, she was only hospitalized a few times. We were able to communicate her needs and body language to the caretakers in a way that we could work together to improve her quality of life at home thanks to the Home and Community Based Service System and the Technology Assisted Waiver Program.

I have no doubt in my mind that I could have never accomplished this at home alone and she would not be with us without this ongoing support system.



Brianna's History, Cont'd

- Brianna is now 19 years old and has been served on the Technology Assisted (TA) Waiver and Home and Community Based Services (HCBS) since birth.
- Brianna has in-home nursing care to help me attend to her medical needs.
- Brianna has a nurse that rides the bus and goes to school with her daily. The nurse is hired by the school system.
- Brianna has access to Personal Service Attendants (PSA)
- Brianna's Quality of Life is Great because of the partnerships we have developed with our agencies, caretakers and teachers.



Philosophy

It takes a village to raise a child.

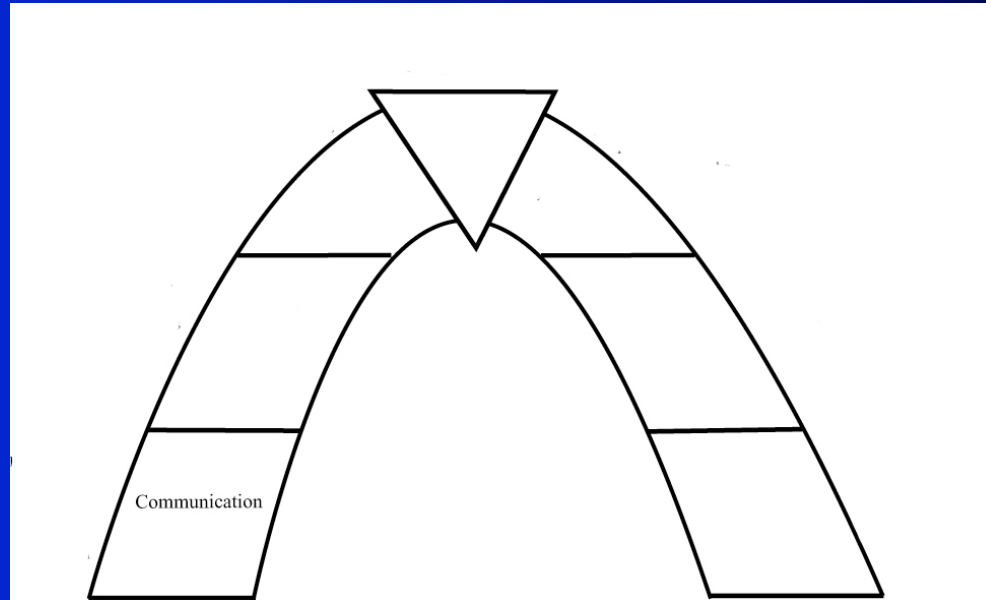
No one expert can know everything about a person with complex needs. We have to work together as a team to help build a better world for people with disabilities and/or complex medical needs and give them a better quality of life.

How can we accomplish that?

Creating Partnerships

The Beach Center for Disability at KU created a visual tool that is research based and shows how Partnership is characterized by 7 principles. Each of these 7 principles are essential elements in a relationship in which families and professionals truly collaborate to achieve a collective wisdom and accomplish a joint goal or outcome. While this tool was created as an Educational model, I feel it works equally as well for partnering with our Home and Community Based System of Supports.

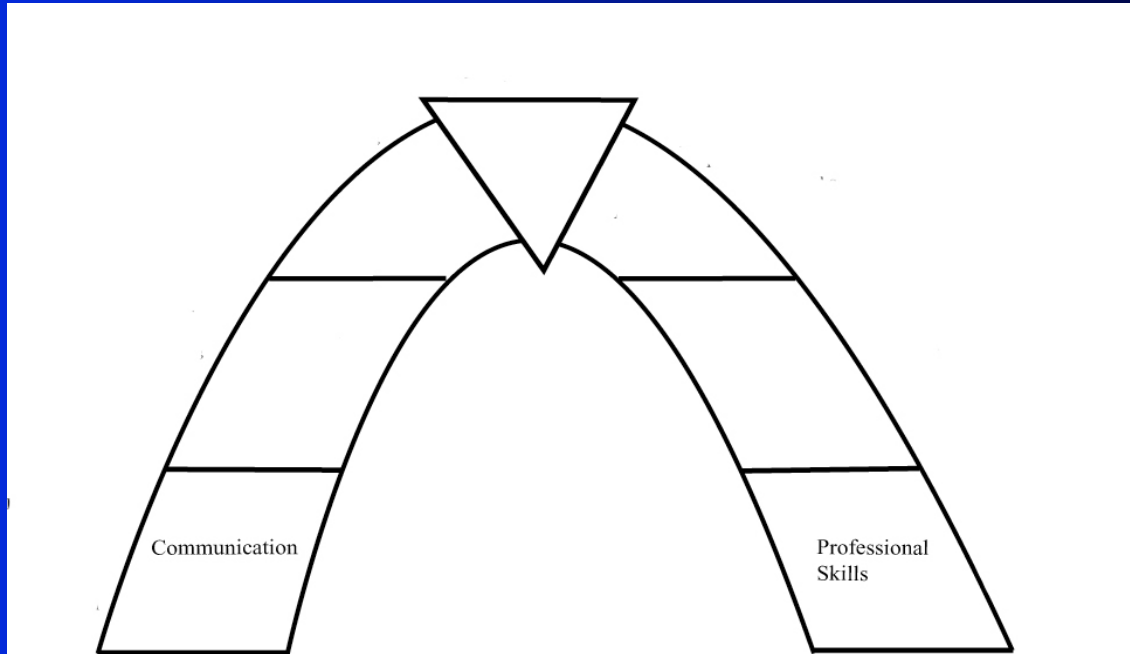
Creating Partnerships



Effective partnerships require effective *Communication*. Research shows the following 5 practices are almost always necessary to ensure effective communication among families and professionals. In order for communication to take place, it is important to:

- Be friendly
- Listen
- Be clear
- Be honest
- Provide and coordinate information

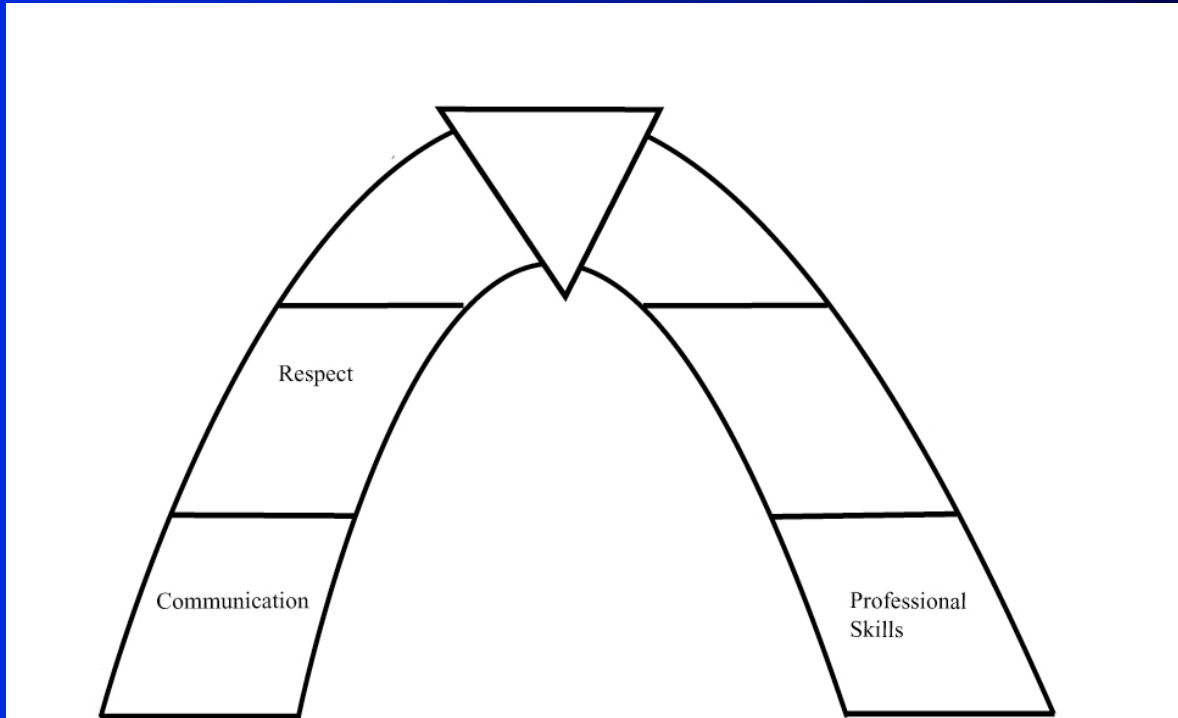
Creating Partnerships



Professional Skills are required of both families and professionals in order to achieve a strong partnership. This includes:

- having high expectations for the individual with a disability as well as yourself
- Continued learning
- Provide quality services and supports

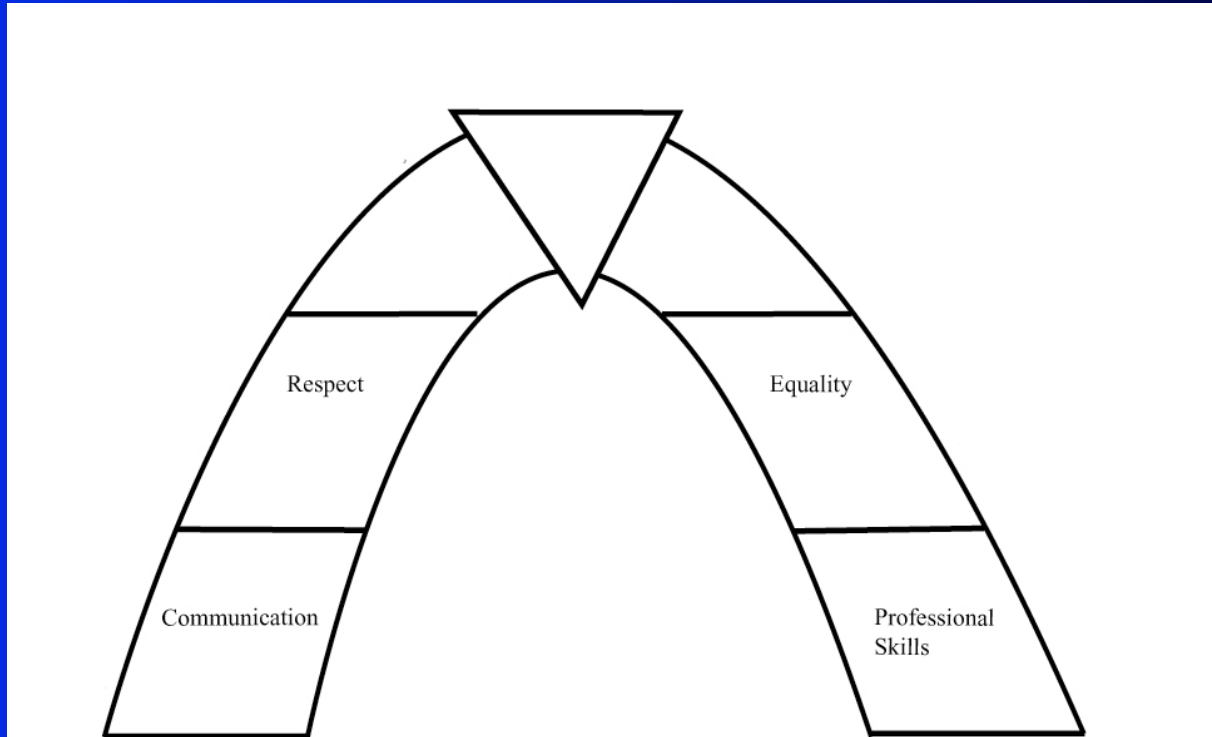
Creating Partnerships



Respect in partnerships means that members value each other and each individual's unique contributions and communicate that value through their words and actions. Showing respect in partnerships means:

- honoring cultural diversity
- affirming strengths
- treating people with dignity.

Creating Partnerships

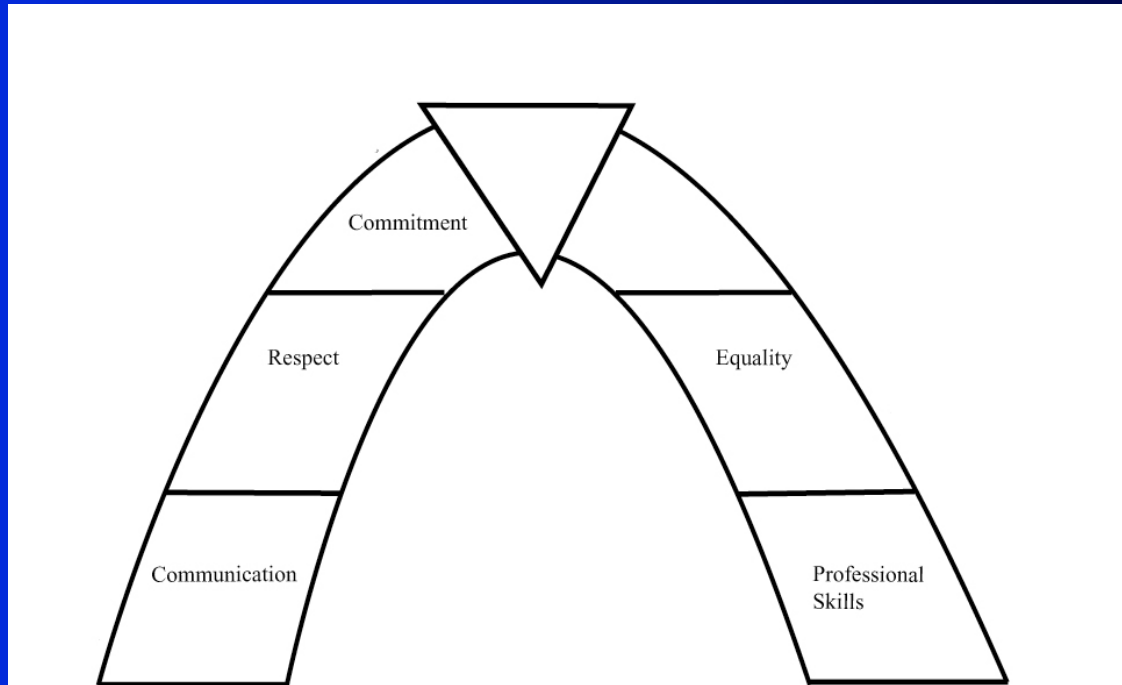


Equality refers to the family and the professionals each feeling that they have a roughly equal power to influence the individual's quality of life.

Equality occurs when families and professionals:

- Share power
- Foster empowerment
- Provide options

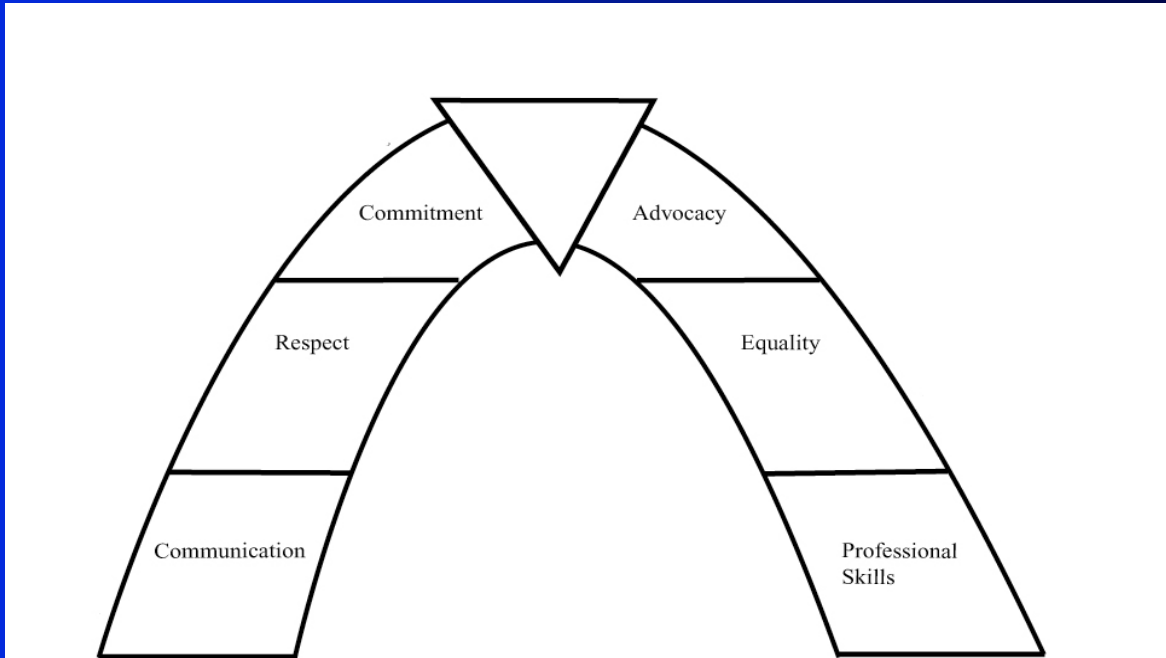
Creating Partnerships



Commitment is reflected when the professional considers their relationship with an individual or family to be more than an obligation incurred through work. As a result the professional:

- Feels loyal and sensitive in working with the individual or family
- Is available and accessible
- Goes above and beyond the call of duty

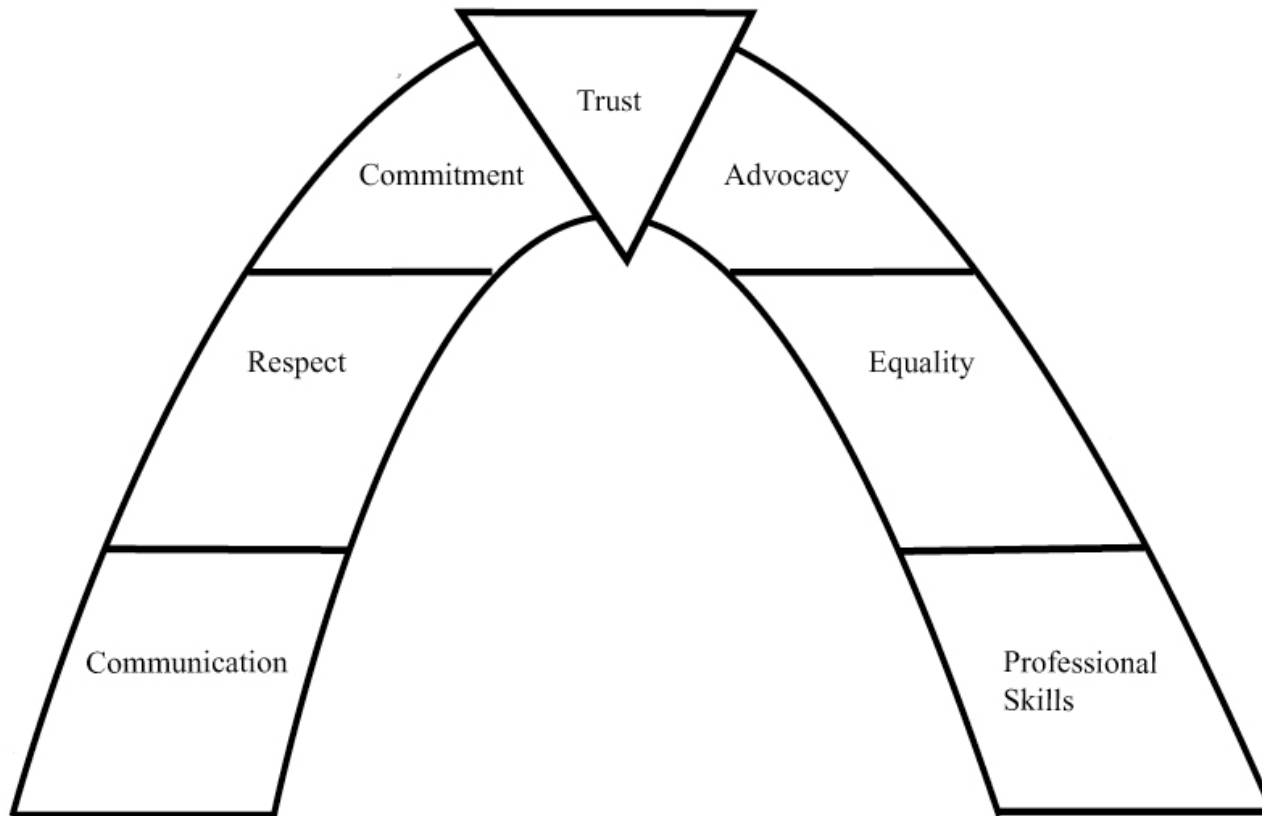
Creating Partnerships



Advocacy refers to speaking out and taking action for a specific cause, such as the individual's support needs or goals. Advocacy is a sign of commitment on the part of the professional. Advocacy can:

- Prevent problems
- Prime your conscience
- Pinpoint and document problems
- Broaden your alliances
- Create win-win solutions

Creating Partnerships



Finally, *Trust* is the keystone of the partnerships arch-it is the piece that holds it all together. Trust is developed over time.

More Ideas on Partnering

- It is important to see Brianna as just another kid
- Be patient
- Be a good observer and listener
- Ask questions
- Know your rights
- Know where to find resources
- I am the expert of my child
- Communication is vital
- Be open-minded
- Think outside the box

Teaching

- I want a nurse/caretaker that embraces the ideal that they are not just there to do things for my daughter, but instead are there to help her learn how to do as much as possible for herself.
- Nurses tend to focus on the medical aspect of the child while PSA's tend to focus on the daily living aspects. It's important for me to communicate clearly what I want them to do as well as why and how.
- We all learn differently-some are auditory, some visual and some people are very hands-on learners. I make a list of what I want them to do and show them, or model the behavior, while explaining it.
- I try not to overwhelm them with too much info at once 😊 Small bits work best at one time when it is new.
- All kids can learn and it is important to have high expectations for them.

Helpful Tips for Partnering

- Create documents with pictures and explanations of how to do things that are important
- Create an “About Me” booklet or brochure for the client to share with their caretakers. It should include information about how they communicate and what they like or don’t like, etc.
- Utilize tools like the Families Together CareING Notebook or app to help you keep medical records organized
- Do a Person Centered Plan
- Empower the nurses/caretakers a sense of ownership by inviting them, agency staff and case managers to school related meetings, like IEP’s, so they will have a vested interest and participate with vital input

Person Centered Planning

- A Tool for planning
- A way of thinking about people that respects their interests, hopes, dreams and desires
- Built on values of inclusion and respect
- Looks at how to involve a person in their community
- Looks at what supports are needed to be successful
- Focuses on how to have a better quality of life
- Might include how to increase their circle of friends

Person Centered Plan-Example

Nick's one page P.C.P.



What people like about me

Gorgeous smile	my singing
Loving	Funny
Infectious laugh	Honest
Cheeky monkey	Caring
Gentle disposition	Style
Chilled out	Determined

How you can support me

Help me access village life
Keep me healthy and safe
Enable me to see friends and family
Help me get to work
Support me with my daily routines
Understand my communication and body language
Talk to me

Things important to me

My drinking cup
My train set
My keyboard
My computer
My music
Family and friends
Routine and going out

My Dreams

My own house
Living a full life
Keeping fit and healthy
Be a valued and contributing citizen

Consumer Self-Direction Google Site

<http://tinyurl.com/ConsumerSelfDirectionSite>

Includes:

- Purpose of Site
- Brianna's History w link to Prezi
- Creating Partnerships
- Personal Experiences with Employer Management
- Functional Areas of Self-Direction
- Self-Direction Toolkit
- Healthcare Notebooks
- Person Centered Plan
- Resources-Documents
- Resources-Kansas Agencies
- Resources-Other
- History of Self-Direction in Kansas

Consumer Self-Direction Resources

[http://tinyurl.com/
ConsumerSelfDirectionResources](http://tinyurl.com/ConsumerSelfDirectionResources)

Includes:

- K-PASS Self-Direction Toolkit (entire and by sections)
- All About Me Book Samples
- Person Centered Plan documents
- Tip Sheet for Creating Partnerships

Thank You!



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